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# ***“The child’s got a complete circle around him”. The care of younger children (5–11 years) with CFS/ME. A qualitative study comparing families’, teachers’ and clinicians’ perspectives’***

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## **Abstract**

Society needs to improve the care of children with complex needs. Guidelines recommend integrating care across health and educational settings, however, there is little research on whether this is achieved or how this can be done in practice. Our aim was to address this gap by examining how the care of children (aged 5–11 years) with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) is shared across home, education and health settings, in order to generate recommendations for integrating care. We undertook semi-structured interviews with families (22 participants), teachers (11 participants) and healthcare providers (9 participants), analysing the data thematically and comparatively. Our analysis of the data was informed by a socio-ecological perspective as we sought to understand the complexity of the relationships and systems around the child. The first theme focuses on the child (“individual level”); child-centred care is seen as essential whilst acknowledging that the child has limited capacity to manage their own care. The second theme presents the distinct roles of parents, teachers and clinicians (“interpersonal and organisational levels”). The third describes how these three levels interact in the management of the child’s care, in the context of the health and education systems and policies (“policy levels”). The fourth explores optimal ways to integrate care across home, school and clinical settings. In conclusion, there is opportunity to support a child with complex health needs by targeting the systems around the child; parents, teachers and clinicians, as well as education and health policy that can enable shared-care. Involving schools in assessment, communicating diagnosis across settings and using a stepped-care approach to integrated care may be beneficial. Further work is needed to explore these recommendations, with attention to the policy factors that may act as barriers and enablers.

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## KEYWORDS

child health, chronic illness in childhood, paediatrics, qualitative research, socio-ecological theory

## 1 | INTRODUCTION

The number of children living with one or more chronic health conditions is on the rise (Lightfoot, Mukherjee, & Sloper, 2001; Perrin, Anderson, & Van Cleave, 2014). These children are often not supported adequately (St Leger, 2014), and there is a need for innovation to improve the care for these children's complex needs (Cornish, 2018). Many of these children spend a substantial amount of time in school, and integrating care across educational and healthcare setting is important (Forrest, 2004; Miller, Recsky, & Armstrong, 2004; St Leger, 2014; Stein, 2001). This is particularly true for younger children (aged 5–11 years) who are dependent on the adults around them for their care (Erickson, Gerstle, & Feldstein, 2005; Tarpey, Caes, & Heary, 2018). Integrating care across health and school settings aligns with UK education policy which recommends inclusive education and managing chronic health conditions within schools (Mukherjee, Lightfoot, & Sloper, 2000).

There are examples of interventions for younger children which span clinical, educational and home settings (Brigden et al., 2019). Bringing health interventions into the school setting can improve health, psycho-social and academic outcomes (Shaw & McCabe, 2008). A multicomponent intervention for children with ADHD included therapist-delivered family behavioural therapy and classroom-administered behaviour therapy with a half-time teaching aide/assistant and teacher consultations (Molina et al., 2009). In combination with medication, this intervention improved pupils' ADHD symptoms, emotional, school, family and social functioning.

Despite the need to better integrate care across these settings, and despite some examples of successful interventions spanning school and clinical settings, there is a lack of guidance on best practice. A review by the Royal Children's Hospital Education Institute (Henry, Edwards, Green, & Meade, 2009) found little evidence on how health and education systems might integrate their practices for children living with chronic health conditions. Intervention development guidelines recommend consulting with stakeholders (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011; Wight, Wimpish, Jepson, & Dos, 2015; Yardley, Ainsworth, Arden-Close, & Muller, 2015), and so the perspectives of families, clinicians and teachers should be gathered to understand this issue of integrated care.

We use the example of CFS/ME to explore the integration of care across health, primary schools and home settings. Paediatric chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME) is relatively common, affecting between 0.1% and 2% of secondary school children (Chalder, Goodman, Wessely, Hotopf, & Meltzer, 2003; Crawley et al., 2012; Crawley, Emond, & Sterne, 2011; Nijhof et al., 2011). In the UK, clinicians provide diagnosis based on the National Institute for Health and Care Excellence (NICE) guidance for CFS/ME diagnosis

### What is known about this topic

- An increasing number of children are living with a chronic health condition.
- Integrating care across educational and healthcare settings is important, particularly for younger children who are dependent on adults for their care.
- However, these children are often not adequately supported at school and there is little evidence on how health and education systems might integrate practice.

### What this paper adds

- This is the first qualitative study to explore the care of younger children with CFS/ME; it suggests that a socio-ecological conceptualisation of care may be beneficial.
- Primary school teachers have close and consistent relationships with their pupils and are well-placed to support their health needs.
- There is little direct contact between clinic and school. This is appropriate for some families, but problematic for those with complex needs.

(NICE produces evidence-based guidance for UK health care commissioners, clinicians, practitioners, managers and the public) (NICE, 2007). Young people must present with disabling fatigue which has persisted for at least three months and which is not explained by other conditions. Key symptoms are post-exertional malaise (an increase in fatigue and symptoms after doing more than usual), cognitive dysfunction, sleep disturbance and chronic pain. Other symptoms may include headaches, painful lymph nodes, sore throat and dizziness and/or nausea. CFS/ME has a significant impact on the lives of young people; it is associated with significant physical disability, school absences, social and emotional difficulties and some children have periods of being bedbound (Bould, Lewis, Emond, & Crawley, 2011; Carter, Edwards, Kronenberger, Michalczyk, & Marshall, 1995; Dowsett & Colby, 1997; Garralda & Rangel, 2004; Patel, Smith, Chalder, & Wessely, 2003). CFS/ME also affects the whole family (Velleman, Collin, Beasant, & Crawley, 2016) and is costly for the Health Service (NHS) (Collin, Bakken, Nazareth, Crawley, & White, 2017). Despite this, it is an overlooked and stigmatised condition (Anderson, Jason, Hlavaty, Porter, & Cudia, 2012). Many children in the UK do not have access to a local specialist service (Baos et al., 2018) and it can take them a considerable length of time to be assessed by a specialist service (Webb et al., 2011). In the UK, the recommended behavioural treatments (Cognitive Behavioural Therapy, Graded Exercise Therapy

and activity management) require the young person to actively monitor and regulate their behaviour (e.g. sleep routines, physical activity levels and taking medication as prescribed).

CFS/ME has been diagnosed in children under 12 years (Davies & Crawley, 2008; Jordan et al., 2006), and disability in this younger age-group is high, with low levels of school attendance, high levels of fatigue, anxiety, functional disability and pain (Davies & Crawley, 2008). NICE guidelines state that healthcare professionals should work closely with education services to develop a common understanding of the child's goals, to offer advice about the child's capability for education and to recommend flexible adaptations to support the child's studies (NICE, 2007). However, the guidelines lack detail on how this should be achieved in practice, they do not address the barriers and they do not provide specific advice for primary school children (NICE, 2007).

## 1.1 | Theoretical background

Child developmental theories describe the distinct physical, emotional, social and cognitive characteristic at earlier stages of development. Across the ages of 5–11 years, there is wide variation in a child's ability to understand and manage ill health. Some children are able to provide sophisticated descriptions of their condition and competently engage in health behaviours (such as self-administering insulin injections). As such, it is vital to inform and involve children as much as they wish (Alderson, 2017). However, at this stage of development children are typically, to a greater or lesser extent, still reliant on the adults around them for support, and so it is "important to understand the larger context within which a child functions ... including family, peers, school and the larger community" (Erickson et al., 2005). Socio-ecological theories help conceptualise the support systems around the child (Bronfenbrenner, 1979; Richard, Gauvin, & Raine, 2011). These models describe multiple "levels" of influence on the health: "individual level" (e.g. beliefs and behaviours), "interpersonal level" (e.g. family and peer support), "organisational level" (e.g. access to and quality of health and education services) and "policy level" (e.g. national and local laws and policy).

There is scope for research which applies socio-ecological models to understand the optimal ways to integrate care across home, school and clinical settings for younger children with CFS/ME.

The aim of this study was to examine the extent to which care of younger children with CFS/ME is integrated across settings. We consider the perspective of families, teachers and clinicians to understand barriers and generate recommendations.

## 2 | METHODS

### 2.1 | Recruitment, setting and sampling

Participants were sampled from two studies with embedded qualitative interviews. EXPLORER is a mixed-methods study investigating

the epidemiology and qualitative experiences of CFS/ME in younger children. EXPLORER recruited children with a diagnosis of CFS/ME aged 5–11 years, between February 2017 and February 2019. MAGENTA is an RCT evaluating two behavioural treatment for paediatric CFS/ME (Brigden et al., 2016). MAGENTA recruited participants aged 8–17 years, with mild to moderate CFS/ME, between September 2015 and March 2018. MAGENTA participants were invited to take part in additional interviews for EXPLORER if they were aged between 8 and 11. This was to ensure that all potential participants (those within the MAGENTA trial, and those who chose not to take part in the trial) were given the opportunity to talk about how their illness affected them. Both studies took place at a large specialist Paediatric CFS/ME service.

Our initial focus was on children, their parents/carers and clinicians. We explored participants' views and experiences of the condition and its treatment. We collected and analysed data simultaneously, and from early analysis, it became apparent that the role of school in the child's care was an important issue. We therefore amended our protocol to extend interviews to school staff (October 2017, see appendix for the notice of amendment). This study synthesised the perspectives of key stakeholders (families, clinicians and teachers).

**Families:** Children aged 5–11 years and their parent/carers, were sampled from EXPLORER and MAGENTA. In both studies, families received an information sheet, which covered the qualitative interviews and families could provide "consent to contact" for the qualitative interviews. From the pool of interested families, we purposefully sampled (Barbour, 2001) for variety in terms of the child's gender, age, school attendance and duration of illness. We invited families to participate in an interview and obtained full written consent/assent from parents and children.

**Clinicians:** Clinicians working in the specialist paediatric CFS/ME service were recruited as part of the EXPLORER study. We purposefully sampled (Barbour, 2001) with the aim of recruiting a range of multi-disciplinary professionals. We provided clinicians with an information sheet, invited them to take part in this study, and obtained written consent.

**School personnel:** Families in EXPLORER were given an information sheet about school interviews and were invited to opt-in and provide written consent to this element of the study. 56.0% of the families ( $n = 28/50$ ) consented. We purposefully sampled schools for variety in terms of the pupil's age and level of school attendance. We contacted schools by phone and by email to provide study information and invite school personnel to take part and we obtained written consent.

Sample size was considered throughout the process of data collection and analysis. Consideration was given to whether new interviews were adding to new insight for the purpose and goals of the analysis (pragmatic saturation), with the acknowledgement that when working reflexively with "rich, complex, 'messy' data" there is always the potential for new understandings or insights (Braun & Clarke, 2019). Consideration was also given to the principle of "information power" (Malterud, Siersma, & Guassora, 2015); whether there was enough

TABLE 1 Participant characteristics

	Number	Sampling characteristics
Families	14 parents. 8 children.	Characteristics of children: <ul style="list-style-type: none"> <li>• 57% (n = 8) female</li> <li>• 5–7yrs = 5, 8–11yrs = 9; Age range = 5–11yrs; Mean = 8.5 yrs</li> <li>• School attendance range 0%–100%; Mean = 60%</li> <li>• Illness duration range 9–63 months; Mean = 24 months</li> <li>• 2 children were interviewed alone, 6 with their parent.</li> </ul>
Teachers <sup>a</sup>	11 school staff	<ul style="list-style-type: none"> <li>• 7x class teachers, 3x head of year/ lead teachers, 1x Specialist Educational Needs Coordinator (SENCO), 1x deputy head, 1x intervention officer (safeguarding and pastoral care) (note some staff members had dual roles).<sup>a</sup></li> <li>• 9x state schools, 2x private schools</li> </ul>
Clinicians	9 clinicians	<ul style="list-style-type: none"> <li>• 5x Psychologists, 2x doctors, 2x physiotherapists</li> </ul>

<sup>a</sup>We refer to teachers rather than school personnel as all but one staff member was a teacher.

quality data to answer the research questions. Recruitment ceased when we felt we had a sufficiently robust sample.

## 2.2 | Data collection

The lead author (AB) undertook face-to-face, semi-structured interviews using a topic guide. Separate topic guides were developed for each participant group, based on literature, the aims of the study and in consultation with two patient and public advisory groups (a CFS/ME young person's advisory group and a public involvement group based in a primary school). Data collection was an iterative process and subsequent topic guides were informed by earlier analyses.

We offered a range of locations for the qualitative interviews and participants could choose their preferred option. This included the University premises (offered to all participants) as we thought participants might want to be interviewed away from their personal and professional spaces. We also wanted to provide an option which reduced the burden of travel, allowed familiarity and comfort for participants and mitigated against the potential power imbalance that could arise from meeting at the University (Elwood & Martin, 2000); and so we also offered interviews at the participants home address (families), workplace (clinicians and teachers) or Via Skype (all adult participants). There was a pragmatic decision to limit interviews to these locations, as we wanted to ensure that the spaces were confidential and conducive to conversation. Interviews were designed to last one hour with adults and 30 min with children. The child could choose to be interviewed alone, or interviewed in a dyad with their parent (Morgan, Ataie, Carder, & Hoffman, 2013). Interviews were audio-recorded and transcribed.

## 2.3 | Data analysis

Anonymised transcripts were imported into the data management software Nvivo. Analysis was thematic (Braun & Clarke, 2006). Firstly, we analysed the datasets separately (within-group analysis of family, clinician and teacher data), beginning with familiarisation with

transcripts, followed by systematic line-by-line coding of transcripts. Codes were reviewed and grouped into broader themes, which were discussed and refined within the research team. Next, we analysed the three datasets by reviewing the within-group themes and comparing and contrasting perspectives across these groups to draw out key areas of convergence and divergence. We focused on the themes relating to integrating care across settings. At this stage, our interpretation of the data was informed by the socio-ecological perspective.

## 2.4 | Ethical approvals

Ethical approvals were granted by the NHS Research Ethics Committee: EXPLORER: 15/06/2017, 16/SW/0335; MAGENTA: 03/07/2015, 15/SW/0124.

## 3 | RESULTS

### 3.1 | Participants

Table 1 summarises participant characteristics. Fourteen families were recruited; 14 parents and eight children were interviewed. Considering the 14 families, eight (57%) children were female. Children's ages were grouped by UK school 'Key Stage' categories: (Department for Education, 2013) five were aged 5–7 years, corresponding to Key Stage One (KS1), and nine were aged 8–11 years, corresponding to Key Stage Two (KS2), with a mean age of 8.5 years. We captured diversity in the duration of illness prior to assessment (9–63 months, mean 19.71) and variation in school attendance (0%–100%, mean 52%).

### 3.2 | Themes

Interpreting the data through the lens of a socio-ecological perspective<sup>31</sup> helped to conceptualise the child within the wider systems. Figure one illustrates the themes within a socio-ecological framework.

The first theme focuses on the child ("individual level"). The second theme presents the distinct roles of parents, teachers and clinicians in relationship with the child ("interpersonal and organisational level"). The third describes how parents, teachers and clinicians interact, in the wider context of health and education policies ("individual, interpersonal, organisational and policy levels"). The fourth explores optimal ways to integrate care across all settings (Figure 1).

### 3.3 | Theme 1. Young children "haven't got the capability": child-centred care is seen as essential whilst acknowledging that the child has limited capacity to self-manage

Teachers, families and clinicians agreed that younger children with CFS/ME, especially those under 8 years, "haven't got the capability" (Parent7) to manage their condition independently. Participants illustrated this reduced "capability" across home, school and clinical settings.

At home, parents described the younger children's inability to understand and adhere to treatment without support, explaining that children "wouldn't comprehend" (Parent7) the treatment plan and do not have the maturity to self-monitor and self-regulate.

*the advice kind of presumed that the person suffering would be able to self-regulate in that way. Kids don't really do that. (Parent6)*

At clinic, most dialogue occurred between the clinician and parent, with children having little engagement "[child] wasn't very responsive... just sat down wouldn't speak" (Parent14).

At school, teachers perceived that these younger children were not as adept at regulating their own behaviour.

*In school not understanding that she needed to stop... she'd run around like crazy and come back in and collapse and be in a lot of pain and then be very upset (Teacher5)*

Teachers and parents also reported that children did not communicate about the condition at school ("he doesn't talk to us a great deal about how he's feeling"). Some children agreed with this ([do you tell anyone at school?] "Not really no", Child4) and for one child this was due to feeling "scared".

*when I'm at school I feel kind of scared to tell people so I don't normally tell like the teacher. (Child12)*

Although participants said that children had limited capacity for self-management, they still emphasised the importance of child-centred care. They spoke about identifying the child's "goals" (Clinician1), "having their voice in the room" (Clinician4), giving them "ownership" (Teacher1), and encouraging the child to communicate.

*Even though it's going to be caregivers who are really following through with the plan, it's still not going to be as successful as if you're engaging with a young person and they have an element of understanding, appropriateness to their age.. we can't lose sight that the young person needs to be involved with their care (Clinician7)*

### 3.4 | Theme 2. "How are we, as the adult supports around this child, going to move things forward": the distinct responsibilities of parents, clinicians and teachers

Children relied on the adults around them, and parents, teachers and clinicians had distinct roles in the child's care:

**Clinicians:** Participants described the clinician's role as providing diagnosis. They then developed treatment plans that spanned the home and school setting, providing advice such as: reducing school attendance ("they [clinician] said only do like four hours of school a day" Child4), structuring rest breaks ("recommendation was that he

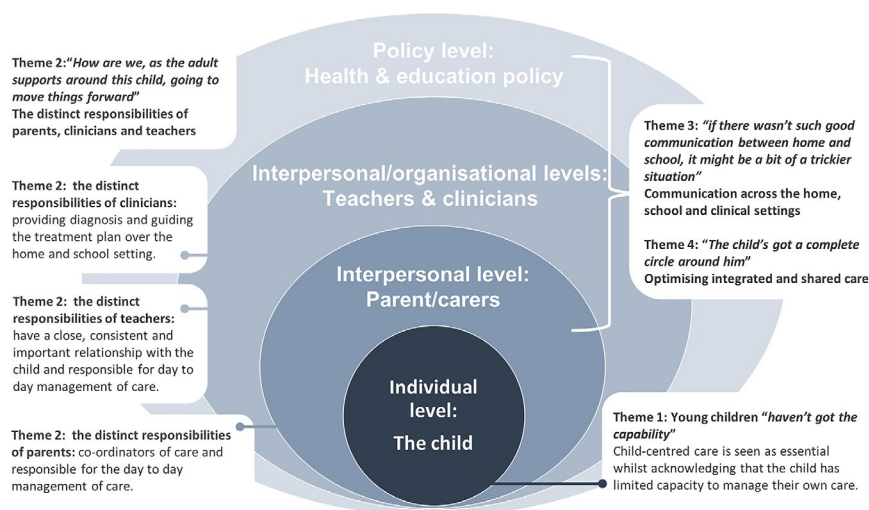


FIGURE 1 Themes, presented within a socio-ecological framework



had regular breaks", Parent9, limiting physical education ("the doctor said to um stop doing PE for a bit" Child12), and making physical and social adaptations in the classroom ("[clinician] suggested things like a medical card so that if she wants to leave the class she just holds the card up", Parent5). The clinician's role was to "review" (Parent2) the child's progress and revise the treatment plan as needed.

**Parents:** All parties viewed parents as the coordinators of care, responsible for relaying information between clinic and school ("The paediatrician guiding his parents and then we're just really going with what is being suggested by [parent]." (Teacher7). They were also primarily responsible for day-to-day supervision of the child's treatment. They monitored their child's symptoms and activity levels ("it's the parents doing it [monitoring activity] really to be perfectly honest", Clinician7); gave their child direct instructions to regulate activity and sleep ("you [parent] tell me to go to bed" Child1); structured the child's environment in line with the treatment plan and administered medication ("If I'm in pain she [parent] gives me tablets" Child4).

**Teachers:** Teachers explained that they had a close and consistent relationship with the child ("he's with me pretty much all day, every day", Teacher1, "[I] get to know each individual child and their families", Teacher8). Clinicians and families also acknowledged this important relationship.

*primary schools, by virtue of looking after children who are younger and more dependent, have a system in place where there's a lot of involved adults who are very key to the child's life (Clinician4)*

Teachers portrayed a proactive attitude to providing support ("we just want to support as much as possible", Teacher7 "I've been very invested in [child] and her health", Teacher5) and all parties recognised their responsibility for day-to-day management of the child's health including: accommodating reduced school timetables ("she is on half a timetable", Teacher6); maintaining a connection with the family during the child's absences ("keep him feeling included and keep feeling as if he was part of the school", Teacher11); structuring the environment to reduce the burden on the child ("like the [classroom], is actually closest to reception so it will be easier for me to get there" Child5); monitoring and regulating the child's activity levels; responding to cognitive, physical and emotional needs; helping the child maintain friendships; and encouraging the child to communicate their needs. Clinicians recognised that "having schools on board with those kinds of things... is just so valuable" (Clinician4).

### 3.5 | Theme 3. "if there wasn't such good communication between home and school, it might be a bit of a trickier situation"; communication across the home, school and clinical settings

Theme three describes the integration of care across settings, including examples of when share-cared is achieved as well as the barriers. The issue of integrated care is complex, and the theme is

derived from parents', teachers' and clinicians' data (children did not express views on this).

#### 3.5.1 | The value of communicating diagnosis across settings

Across the datasets, participants talked about the importance of sharing the diagnosis across settings. Parents described the impact of diagnosis, the "relief that... somebody has listened" (Parent8), feeling "believed" (Parent2) and felt it was important that clinic communicated this directly to school.

*if there's someone, other than me, going in and saying, he has this condition... to back that up and say actually, they're not just trying to take their child out of school, he does have a medical condition and it does need this (Parent2)*

Both teachers and families identified diagnosis as a catalyst to the school taking the health concerns seriously and implementing the necessary support. Teachers emphasised that at an organisation/policy level, teachers needed this formal diagnosis to implement treatment recommendations, such as reduced timetables.

*we had the letter with the formal diagnosis on it... [school] agreed without hesitation we had the back-up letter from the consultant so it all went really smoothly (Teacher8)*

#### 3.5.2 | Variation in experiences of ongoing communication across settings

All parties highlighted the lack of ongoing direct communication between clinic and school. Teachers reported minimal contact from clinicians ("the school hasn't had any direct contact", Teacher5, "not an awful lot came back to school", Teacher8) typically consisting of "two or three letters" (Teacher 6).

In some cases, this limited direct contact was acceptable to schools, ("that's fine [a copy of clinic letter] I don't really need to know too much more", Teacher9). However, there were cases where families, schools and clinicians identified this minimal contact as insufficient. In the latter cases, schools viewed direct input from the clinical service as "really vital" (Teacher4), and were dismayed that teachers held high levels of responsibility for the child's health with little guidance:

*I basically made it up as I went along... trial and error... the clinic maybe it would have been helpful to have a guideline... we had no idea at all... didn't know with like her attendance... her sleeping in class... we've had to do like a risk assessment for her... without any kind of guidance...*

*didn't know if it was the right thing or the wrong thing either really, I think that was the scariest part (Teacher5)*

In these latter cases, there was a level of frustration from all parties. Teachers expressed frustration about the limited input from clinicians ("it's very hard to get health around the table", Teacher4). Families reported that schools "didn't believe it" (Parent12), "they didn't adapt to [child's] needs" (Parent3) and created "lot of resistance" (Parent11). Equally, clinicians were frustrated by the lack of support from schools "sometimes the school are a bit obstructive to be honest" (Clinician 7). Clinicians and teachers did not always hold individuals responsible, instead noting organisational/policy; limited resources in schools ("It varies [school support]... it depends on the resources they've got there", Clinician 8) and health services.

*it's not that it wouldn't be appropriate [direct liaison with teachers] but any professionals meeting has completely been pulled back because of demands clinically... it's about demands we have as clinicians that has to be prioritised (Clinician7)*

Synthesises across-datasets revealed agreement on the factors associated with satisfaction or dissatisfaction with the low levels of direct clinic-school contact:

#### 1. Relationship/ communication between parents and schools:

Teachers satisfied with minimal clinical input attributed this to "effective" communication between parents and school. This allowed teachers to gain an understanding of the condition, "mum explained it" (Teacher2), receive updates from clinical appointments "she [parent] would come back and report on what they had said" (Teacher1) and collaboratively develop a plan of support. They believed "it's the most important thing for the family to communicate with the school" (Teacher2).

*it probably does depend on the parent being quite proactive in that situation ... checking in regularly with her and so it's working fine... if there wasn't such good communication between home and school, it might be a bit of a trickier situation... we might have been more proactive in terms of finding out more [from clinic] (Teacher7)*

Clinicians believed it was important to empower parents to liaise with school ("you don't want to sort of take some of the responsibility of the parents away", Clinician8).

In contrast, teachers wanting more support from clinicians reported challenges in communicating with parents "I've been trying to contact mum, but I haven't had any luck" (Teacher4) and said that direct communication with clinic was needed when parents did not have the capacity to communicate.

*not an awful lot came back to school... mum had so much on her plate... she became quite unwell herself, to then expect the parent to liaise with the school it was just*

*one step too far... if we'd have got some formal feedback from the consultant about what we could have done (Teacher8)*

Clinicians echoed this sentiment, recognising fractious relationship between families and school was a marker to intervene directly with schools.

*the relationship had kind of broken down a bit between the family and, the school and I think actually the parent had said they wanted [a clinician] to go in to explain about what chronic fatigue was, which I thought was wholly appropriate (Clinician1)*

2. Goals for the child's education aligned: Those teachers satisfied without direct communication from clinicians described the parent as prioritising education ("the parents are trying to make sure their education was still at the forefront of everything", Teacher1). Conversely, teachers wanting more health input were in tension with parents about how much the child could/should be attending.

*mum was kind of like... I can't force her to [attend]. But for me the school needs to keep pushing for her to come in a little bit more... although she has these symptoms, I think we could help them at school more if she was here for a longer period (Teacher3)*

Equally, parents had negative perceptions of schools when they perceived this mismatch and saw schools as "more concerned about their targets" (Parent9).

3. Complexity and severity: Teachers managing without direct intervention from clinicians talked about cases being "straightforward" (Teacher7). They described low levels of absenteeism ("he hasn't missed loads", Teacher1, "his attendance has been pretty good", Teacher7), fewer concerns over emotional well-being ("he's a fun, bubbly little boy", Teacher7), believed that the child was keeping-up academically and recovering from the illness.

*I don't think [more support from clinic was needed] because we could see that it was improving quite quickly (Teacher1)*

By contrast, those keen for more guidance were concerned with high levels of absenteeism ("[child] was spending very little time with us" (Teacher10), "she really hasn't been here for the last almost half year", Teacher4) and academic difficulties ("really wasn't making any academic progress", Teacher8, "she was really behind" (Teacher3). Teachers also described a more complex clinical picture, with multiple-diagnoses and multiple professionals involved ("there's safeguarding and pastoral issues", Teacher4).

Equally, some clinicians differentiated between simple and complex cases. In simple cases they stated "it is very much up to the parents and the school to kind of put these boundaries in place and to have



really good communication links" (Clinician6), but they believed their direct intervention with school was "something you could justify for complex children" (Clinician3). They advocated starting without direct communication with schools, moving to direct communication if the case became challenging:

*You start off with the basics and if it all goes fine, then that's good. But then if it's not really working out then its further down the line you might make contact with the school (Clinician7)*

### 3.6 | Theme 4: "The child's got a complete circle around him"; optimising integrated and shared-care

Participants provided perspectives on how shared-care could be optimised. Considering the process of diagnosis, clinicians identified the increased complexity of assessing younger children ("with younger children it's that much more complicated", Clinician4), and discussed the potential benefits of involving schools in this process ("in that assessment process a school's observation of the child could be really helpful", Clinician4). Teachers expressed a desire to provide formal reports to clinicians to aid assessment. They compiled such reports for other clinical conditions (ASD, ADHD) and believed it was important to provide "the schools' perspective on how the child presents in school" (Teacher1). They stated their privileged position of a professional perspective along with a close relationship with the child could be beneficial to the clinician:

*mum has judged what she's like in the classroom whereas the judgement should probably come from the teacher who knows what she's doing in that environment (Teacher6)*

Parents did not explicitly discuss the need to involve teachers in assessment, but acknowledged the insight that teachers had about the child:

*[teacher] said that actually they'd noticed a difference in class, he wasn't as switched on as usual he wasn't as focussed, he kind of tended to lose concentration which we probably wouldn't of picked those things up (Parent9)*

Families and teachers satisfied with limited direct contact between clinicians and school still highlighted ways to optimise care. Teachers wanted generic information provision in the form of leaflets and signposting to resources to empower the school to manage their pupil. They reported a lack of information in this format ("I've never ever seen any for it at all", Teacher1) and compared this to resources available for other medical issues (allergies/epi-pen, asthma, diabetes, ADHD, ASD, Crohn's, epilepsy, dyslexia dyspraxia and the learning conditions). They also thought that the child could be supported to take information from clinical consultations to their teacher:

*I think it really would be good to be able to do the plan for chronic fatigue for their day, in a way that was the young person was able to take it into school and say 'this is my plan'. (Clinician7)*

Teachers, parents and clinicians who emphasised the need for direct communication between schools and clinic wanted "direct conversation with professionals" (Teacher4) for clearer advice about the child's "individual" needs and "personalised" guidance on how the school could manage their health needs. They believed that telephone, emails and face to face meetings between clinicians and teachers could be beneficial.

*I would have loved it if I could have sat down in a room with somebody who could just say...this is [child], this is how it affects [child]. These are the things you can do to help... someone from an outside kind of you know who-who is an expert (Teacher3)*

They also wanted multi-disciplinary meetings ("professionals in the room", Teacher4), classroom observations ("it would be useful to someone actually to come in and see [child] in the actual school environment", Teacher6) and training sessions. Clinicians differentiated between simple and complex cases (considering complexity of clinical presentation in terms of illness severity, co-morbidities and other professionals involved) and clinicians agreed that telephone and face to face meetings could be beneficial for complex cases ("telephone to schools are always helpful. They always help to manage things better than just writing letters", Clinician6; "the cases that I've worked best with school is the one where I've done regular meetings with school especially at primary school age", Clinician4). Parents valued direct contact between clinic and school in the minority of cases where this happened:

*[Clinician] was very good because contacted [school] and spoke to the special educational needs person and explained everything to them so they're different then cause they understand (Parent5)*

## 4 | DISCUSSION

To our knowledge, this is the first paper exploring integrated care across education, home and health settings for younger children with CFS/ME. This study highlights the relevance of a socio-ecological perspective. The greatest opportunity for supporting the child with a chronic health condition comes from targeting the systems around the child; the parents, teachers and clinicians, as well as the education and health policies that can enable shared-care.

Parents are responsible for coordinating care between schools and clinic, and there is typically minimal direct contact between clinics and school. When families and schools communicate effectively and where the child has fewer complex needs (considering complexity in terms of challenges in the family-school relationship,

severity of the illness, co-morbidities and other professionals involved) this works effectively and could be improved with generic information provision from clinic. However, we identified a subset of cases where direct contact between clinics and school was needed; taking the form of face to face or telephone meetings or emails. Funding levels in health and education services limit the extent to which clinicians can work directly with schools, and the extent to which teachers can implement individual treatment plans for their pupils.

Strengths of this study include the synthesis of multiple perspectives, a large sample size, purposive sampling and robust methods for analysis. We synthesised the views of parents, clinicians and teachers, which is rarely done (Cabral, Lucas, Ingram, Hay, & Horwood, 2015), providing a rich understanding of the issues of integrated care. We recruited a heterogeneous sample of children in terms of their age, gender, illness duration, school attendance and using Skype allowed us to include families from across the UK. Multiple researchers reviewed data and supported theme development. We attended to negative/ deviant cases (Mays & Pope, 2000), represented both convergent and divergent views, and interpreted the different perspectives in relation to theory and implications for practice.

Families and clinicians were recruited from one service. However, this is the largest specialist paediatric CFS/ME service in the UK offering a service to children across the nation due to a lack of local paediatric service provision (particularly for children under 12). Recruiting families engaged with a specialist CFS/ME clinical service limits the transferability of findings to families not in contact with such services. We recruited from the MAGENTA RCT, and participants taking part in a trial may not be representative of a typical population. However, we also recruited children who do not enter this trial, recruiting via the EXPLORER cohort study.

We recruited schools from counties across the South-West of England. NICE guidelines and national health and education policy should apply uniformly across the UK, however, the paediatric service is the largest in the UK (and established for 15 years) therefore issues facing schools without a local or well-established service may be different. We did not sample schools based on the socio-economic status of the local community, and therefore we cannot say if we captured diversity in this respect. Some teachers declined/ did not respond to our invite, and we acknowledge that those who self-selected into the study may be more proactive/positive about supporting CFS/ME.

We used dyadic interviews where there is potential for parent-child dynamics to influence interviews, and lead to greater weight being given to the parent's voice. However, dyadic interviews can increase a child's confidence, and we found that in most cases the comments from parents prompted and drew forth richer responses from children. We also worked hard to hear the child's voice by using art-based methods (Coad, 2007) and by offering individual interviews for those children who wished to tell their stories independently.

Although children display a range of abilities in managing their condition, most still rely on the adults around them for support, and so the socio-ecological framework should underpin treatment approaches; interventions should target the child and the systems around them. Using a socio-ecological framework is consistent with contemporary approaches to paediatric healthcare delivery (Hilliard, Powell, & Anderson, 2016; Mosnaim et al., 2016; Naar-King, Podolski, Ellis, Frey, & Templin, 2006).

Currently, the assessment of paediatric CFS/ME typically involves parents and children. This paper suggests that the teacher's perspective could also be valuable during the assessment process. Involving teachers at assessment is an approach used in other paediatric conditions, for example ADHD (Atkinson & Hollis, 2010). Further work to explore the feasibility and acceptability for families, clinicians and teachers would be needed before adopting this approach in paediatric CFS/ME services. Our findings highlighted the importance of communicating diagnosis to school in an effective and timely manner; this is consistent with other studies which have identified "*the power of diagnosis*", (theme 3 from (Tarpey et al., 2018) in eliciting engagement from schools (Mukherjee et al., 2000; Tarpey et al., 2018). CFS/ME is a stigmatised condition, it is often poorly understood by the public and we found that many teachers did not have a formal knowledge of the condition. In this context, sharing diagnosis with teachers may be particularly important; it provides clinician confirmation of the authenticity of illness and the need for ongoing support (Nettleton, 2006). This helpful role of diagnosis contradicts historical arguments that the diagnosis of CFS/ME in younger children is damaging (Harris & Taitz, 1989).

Effective communication between health and education systems is important for supporting children with chronic health conditions (Forrest, 2004; Miller et al., 2004; St Leger, 2014; Stein, 2001), but there is no clear consensus on what this looks like in practice. We found that in many cases the clinical services can empower families to coordinate care. However, in more complex cases, direct contact between clinics and school is needed. As such, we suggest that an appropriate approach would be a stepped-care model (Bower & Gilbody, 2005) where intensive communication between school and clinic is only provided for those with more complex needs. Stepped-care models use the least costly, least intensive and least restrictive treatments which empower patients and makes efficient use of finite resource (Donovan & Marlatt, 1993).

We identified organisational/policy factors that act as barriers to integrated care. Noting these factors is important, as a shift is often needed at this level to produce bigger changes further down the system (Meadows, 1999).

## 5 | CONCLUSIONS

We recommend involving schools in the assessment process, communicating diagnosis across settings and a stepped-care approach to integrating care across clinical, school and home settings. Further work is needed to explore these recommendations,

with attention to the policy factors that may act as barriers and enablers.

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## CONFLICTS OF INTEREST

EC is an unpaid medical advisor for the Sussex & Kent ME/CFS Society.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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